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ABSTRACT

The paper discusses the birth of a mentally retarded infant in terms of initial parent reactions, adjustment, decision to institutionalize, psychological effect on the mother, psychological effect on the father, impact on the marriage, and impact on siblings. The birth is a traumatic experience for the parents and can result in initial feelings of shock, grief, guilt, and shame, giving way to a general sense of depression, lowered self esteem, and lack of enjoyment of the handicapped child. Sensitive informed counseling is necessary, not only immediately but throughout the life cycle of the family. The thrust of early intervention programs with high risk infants is toward helping the parents stimulate their child to maximize cognitive and social/emotional development. It would not be too difficult to expand the function of these programs to provide the necessary counseling for parents and siblings of the handicapped child. Group counseling both for parents and siblings has been shown to be highly effective in helping parents and siblings express their feelings with regard to the handicapped child. Bringing parents together with like problems also facilitates parent to parent counseling and assistance. (Author/SB)

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PSYCHOLOGICAL EFFECTS ON THE FAMILY OF A MENTALLY RETARDED CHILD*

by
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Introduction

Parental expectations around the birth of a child are high. Parents often fantasize about the accomplishments of their anticipated heir. At the very least, they hope their child will be able to surpass their own achievements and be free from the flaws that they detect in themselves. Often, parental expectations (first child) for family life are idealized, taking their cue from television families where only minor disruptions interfere with the harmonious flow of day to day activities.

All of these dreams and fantasies are abruptly severed when the parents are notified that their child is deficient in some manner. In some cases, (Downs Syndrome) the abnormality is detected at birth. In others, the parents gradually recognize that their child is not meeting the normal milestones of growth and development. Then, it is either a pediatrician or school personnel who confirm the parents' fears that their child is intellectually impaired.

A parent's ability to cope with and accept a mentally handicapped child is a result of the interaction of many variables, i.e., the parent's socio-economic background, education, success orientation, the severity of the child's handicap, the sex of the child and the number of other normal children in the family. It has been suggested that to understand the parent's reaction one needs

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to know what the handicapped child's situation means to the parents.[1] For example, to the parents who have highly internalized this society's success oriented values, the birth of a handicapped child will be a traumatic event.

Generally, the literature recognizes that the parents' reactions will vary according to the nature of the handicap. Three groups of parents have been identified -- those of mentally handicapped children, physically handicapped children, and emotionally disturbed children. This paper is limited to the study of the family of a mentally handicapped child. However, the literature indicates that parents of severely physically handicapped children share many of the same reactions, feelings, and frustrations. The writer has also chosen to include research on siblings of the mentally handicapped child since it has become evident that professionals working with the family of a mentally handicapped child should not overlook or underestimate the degree of tension experienced by the siblings of a mentally handicapped child.

Initial Reactions

General agreement exists in the literature as to the initial emotional reactions of a parent to the birth of a handicapped child.[2] Shock accompanies the initial diagnosis confirming the handicap. The parents' cherished plans for their child are abruptly terminated. There follows a period of grief and mourning for the loss of their "idealized" child. Realization of the discrepancy between the anticipated child and the real child creates a crisis situation for the parents. Depending upon the parent a variety of defense mechanisms may be employed. Frequently, the parents deny the diagnosis, sometimes seeking help from other professionals hoping that their child will be found normal or that a remedial cause will be discovered.

Guilt also appears to universally affect the parents of a mentally retarded child. Parents feel that in some way they are responsible for their child's condition. They may seize upon some past behavior of theirs as an explanation for the child's condition. The unspoken or unconscious wish that the child had died or would die heightens the parent's sense of guilt.

Anger and bitterness are parental reactions when they realize the extent to which the handicapped child will interfere with their personal plans and drain their financial resources. The accompanying disappointment and frustration with the child further exacerbates the parent's anger and bitterness. Also, parents may turn their anger and bitterness towards each other and themselves for bringing the child into the world.

Shame and loss of self esteem also accompany the realization of the child's deficiency. The parents see the child's defect as a reflection on themselves as they were not able to "produce" a normal child.

Adjustment

While in the past professionals were primarily interested in the child and his/her problems, it is now being widely recognized that the parents of mentally handicapped children are equally in need of help. Services to the parents are necessary in two categories: (1) parents need adequate knowledge regarding the etiology of the handicap and appropriate ways of interacting with their child, i.e., educational programs; and (2) parents need counseling to help them recognize and deal with their feelings around the handicapped child.[3]

The earlier that guidance and counseling programs are initiated, the more likely parents are to make an adequate adjustment to their child. Also, the sooner programs of stimulation are begun with children, the more likely they are

to reach their maximum potential. Since parental attitudes towards the handicapped child are modeled by the siblings, the need for early intervention with parents is further justified.

An educational program with the parents should include a discussion of the etiology of the child's condition to help the parents handle their guilt and shame reactions. When the mental retardation is discovered at an early age, parents should be trained in ways in which they can stimulate their child's social/emotional/cognitive development. Often seriously handicapped infants initially place fewer demands on parents as they are "good" babies, lying quietly and not demanding attention. Too, the infants provide the parents with little positive feedback as eye contacts, smiles, attempts to verbalize, etc. Early intervention programs have found that a program of stimulation carried out by the parent with their seriously retarded infant helps to offset the negative downward spiral of interaction that often develops between the handicapped infant and his/her parents.[4]

Simon Olshansky suggests that parents of a mentally handicapped child suffer from "chronic sorrow."[5] Olshansky recommends that professionals accept the parents' sorrow, considering it a natural rather than a neurotic state. According to Olshansky, the counseling process with parents needs to be extended for many years, on an open door basis, giving parents many opportunities to discuss their feelings and problems associated with their mentally handicapped child.

The Decision to Institutionalize

Professional attitudes have changed rapidly during the last decade with regard to institutional placement for the mentally retarded child. The current philosophy is that of "normalization," i.e., the child should be kept in as normal

an environment as possible. It is felt that the individual's chances for personal development -- cognitive, social, emotional -- is greater when kept at home or in a small community residence where normal interactions are maximized. Ten years ago parents with a severely retarded child were advised to institutionalize their child immediately before they became attached to "it."

Parents have been caught unfairly in this professional see-saw. Those parents who ten years ago chose to keep their child at home were made to feel guilty. "Think of the damage to the family - to his siblings, to you the parents, to your marriage - if you keep him at home."[6] Now parents are made to feel equally as guilty if they do chose to institionalize their children. Many professionals who offer glib advice to parents about the positive benefits to the child of remaining at home have no clear idea of the unceasing strain that the child places on the family. "What is most difficult I think, in day to day living with a retarded child is that there is no end in sight. Just an eternity of babydom."[7]

Factors to be weighed when considering residential placement for a mentally handicapped child are the strain on the marriage itself, the mental/emotional health of the parents - especially the mother - and the effects of the mentally handicapped child on the other children within the family.

Various studies have shown the unfavorable effects on an older female sibling when the care and responsibility for a handicapped child falls on her shoulders.[8] However, there is evidence to suggest that when family resources are such that they can cope with the handicapped child without placing undue demands on the other siblings, the normal siblings cope more adequately with their sister or brother's retardation if the child is kept at home.[9] For

example, brothers and sisters of the institutionalized child may develop fear and anxiety that they too will be excluded from the family. Also, siblings often experience guilt in that they were somehow the cause of their brother or sister's institutional placement. Elaborate fantasies around the handicapped brother or sister's condition may build up when the handicapped child is institutionalized or seen infrequently. Keeping the retarded child at home allows the normal child to cope more successfully with the retardation and experience less guilt.

The decision as to whether or not to institutionalize a child is extremely difficult and complex. A variety of factors need to be considered -- the severity of the handicap, the emotional status of the parents, especially the mother, the age, sex, and number of other children in the family, and the financial/community resources available to the family. Professionals should provide parents with information and support; however, each situation is unique and can only be decided by the family members, themselves.

Psychological Effects on the Mother

That mothers of mentally retarded children experience greater psychological stress than mothers of normal children is no surprise. Not only does the mother frequently have greater demands on her time and energy with respect to direct child care, but she also spends an inordinate amount of time "shopping" for help from professionals and agencies. It should be pointed out here that parents often "shop" around twice, the first time as a result of the denial process, and the second time to find appropriate services and help for their child to maximize his/her potential. Due to the sex role division in our society, it is the mother in most cases who seeks out professional help for her child. The mother may spend years being shuffled from one professional to another trying to find

the cause of her child's difficulty or proper services. She may be given an array of diagnoses and labels for her child depending upon the specialist's background and training. Imagine the parent's frustration when the resulting diagnosis is "delayed development of unknown etiology."[10]

Again, because the primary role of child care falls upon the mother, it is she who must either find someone to care for the child at home or suffer the rude stares, pitying looks, and/or embarassing questions of neighbors, friends, and onlookers when she takes the child with her. She is not allowed to forget for one minute that her child is different. Birthday parties, holiday gatherings with family, neighborhood coffee klatches all become difficult times. It often becomes easier not to socialize with friends and neighbors. In addition, envy and jealousy of those who do not have an exceptional child frequently occurs.[11]

The mentally handicapped child is usually unable to play with his/her age peers for lack of appropriate social skills. Often, the child is taunted by age mates with names such as "retard" or worse. It is most often the mother who witnesses the child's frustration.

The effects on the mother's personality as a result of having a mentally retarded child has been investigated.[12] Subjects in this study were the natural mothers of the child, with the handicapped child in the age range of 4-21. The mothers were all from intact families and had other normal children in the home. Results showed that mothers of a mentally handicapped child as compared with mothers of only normal children had significantly greater feelings of depression, along with preoccupation with the child and difficulty in handling anger at the child. Sense of maternal competence was low. One of the clearest results of the study was the lack of enjoyment of the child experienced by the mother. The

results suggest a bleak picture of depression and hopelessness on the mother's part, coupled with anger at the child and rejection. Loss of self-esteem appears likely. The authors note that the results most likely underestimate the extent of the psychological stress on the mother due to several features of the methodology -- primarily the choice of intact families as subjects and self administration of the test batteries.

Psychological Effect on the Father

In the past, the sex role division in our society has allowed the father to "escape" from many of the direct care responsibilities of the handicapped child. Some fathers have been able to put off coming to grips with the child's deficiency until the child was of school age. Male patterns of socialization (against expression of feelings) have most likely kept many fathers from expressing their anxieties and fears about their handicapped child. However, the growing determination of mothers to maintain a career outside of the home coupled with the mother's demands that child care be more equitably shared, now places additional responsibility and focus on the father.

Little research has been done directly on the father; however, a companion study on fathers to the research previously cited on mothers has been reported.[13] Subjects again, were from intact families, the natural fathers of the child, had fathered at least one normal child, and had a retarded child in the age range of from 4-21. Results showed that fathers of a mentally handicapped child as compared with fathers of normal children had significantly greater feelings of depression and preoccupation with the child. General self-esteem was lower as was esteem derived from the paternal role. The fathers, as the mothers, showed little enjoyment of the handicapped child. Further the fathers' lack of

enjoyment of their handicapped children generalized to their normal children and wives. Lowered gratifications from these other significant relationships were also noted. Finally, a moderate amount of rejection for the handicapped child was shown.

A comparison of results suggests that both mothers and fathers are deeply affected by the retarded child and that it is a psychologically stressful experience for both. While fathers may "escape" each day, from the continuous care of the handicapped child, it is clear that fathers experience significant stress none-the-less.

With regard to lowered self-esteem, the writer would like to share a personal experience which would corroborate the findings that fathers of the handicapped suffer ego damage. A second child, a son, was born to the writer's parents two years after her birth. The child was handicapped and lived less than a year. To this day, the writer has no idea as to the nature of the handicap as my father insisted that all memorablia regarding the child be destroyed and that the topic never be discussed. Years later the writer's mother indicated that the father felt that the child's deficiency reflected upon his role as a "begettor" and thus desired the subject as well as the child buried.

Impact on the Marriage

Several studies suggest that increased marital conflict accompanies a mentally retarded child in the family.[14] Since increased psychological stress has been shown to be a concomitant of having a handicapped child in the family, it appears self evident that increased marital conflict would result. Latent conflict may become open warfare or an already deteriorating marriage may be hastened by the arrival of a mentally handicapped child. In addition, anger at

the child may be displaced upon the marital partner. (It is more acceptable to be angry at one's spouse than at a helpless child.)

For many parents a handicapped child puts an additional strain on already limited financial resources, forcing families to abandon cherished dreams, travel, and recreational activities. Social activities and travel also are inhibited by the parent's inability to find adequate baby sitters or care facilities. Parents of normal teenagers welcome the relative freedom from unending child care responsibilities. Parents of a mentally handicapped child cannot look forward to a time when they will be free from the incessant worries that a totally dependent child creates. Parents, too, worry about what will happen to the child when they are gone. Sexual relationships may be hindered by the fear of producing another handicapped child. Husband or wife may harbor resentment towards one another especially if the child was unplanned.[15]

Impact on Brothers and Sisters

Normal siblings of a retarded child frequently struggle with the question, "If I have a handicapped brother or sister, does that mean something must be wrong with me, too?"[16] The curiosity and need for knowledge that is engendered by these thoughts is often left unsatisfied. In general, parents of mentally retarded children have difficulty openly discussing the retarded child's condition with other family members. Adolescents report that talking about their siblings' retardation with their parents was like talking about sex. Clearly, many questions were left unasked and unanswered.[17]

The lack of information regarding the handicapped child's condition may be the impetus for unreasonable fears and elaborate fantasies on the part of the normal child.[18] When parent's institutionalize a retarded child while the child

is still young and there is little or no contact between the siblings and the retarded child, the curiosity and anxiety are intensified.[19]

It is absolutely imperative that children be given as much information as possible about their handicapped sibling and that interaction with the handicapped sibling be maintained to the greatest extent possible. This will allay the normal child's fears and anxieties and allow the normal child to cope more adequately with the fact of the sibling's retardation.

One of the main tasks of siblings of retarded children is to avoid identifying with the retarded sister or brother. Grossman found during group counseling with siblings of retarded children that it was extremely important for the normal siblings to maximize the differences between themselves and the retarded child. In other words, they almost desperately needed to establish their own identify as distinct from the handicapped sibling.[20] Other concerns of adolescent siblings of retarded children were: (1) the extent of awareness of the retarded child as to his/her difference; (2) discipline and control of the retarded sibling; (3) the relationship between their family, neighbors, and the larger community vis a vis the retarded child; and (4) what and if they should tell their friends about their retarded sibling.[21]

In addition to her counseling work with adolescents, Grossman carried out a formal research study which focused on 83 college siblings of retarded children. Groups were divided on the basis of sex and private vs. community college attendance. Grossman reports that the sample is most likely biased in that those students who volunteered for the study most likely came from families less traumatized by the sibling's retardation than those who did not volunteer. Therefore, it is suggested that negative findings would probably be greater in a more complete sample.[22]

The study found that families of students who attended private colleges had the financial resources to minimize the hardships and inconveniences that a mentally retarded child presents to the family. Therefore in these settings, the effects of the retarded child on the family are primarily psychological. The normal child's perception of his/her parent's reaction to the handicapped child was the deciding factor in how the sibling experienced or related to the child. In contrast, siblings in the community college cohort felt the impact of the retarded child in the sense of real hardships. Family financial resources were drained and a major investment of time and effort were expended in the care of the retarded child. For women in this group, the more severe the physical handicap of the retarded child, the less their coping effectiveness score. (It is presumed that older female siblings of a mentally handicapped child are pressed into child care activities with the child.) Interestingly, the more severe the mental handicap with the physical handicap controlled, the better the coping effectiveness. Apparently siblings feel pain and anxiety over the mildly handicapped child's inability to cope socially and academically. They report that the mildly handicapped child knows something is wrong but doesn't understand what, and that people are cruel to the child seeing no apparent reason for his/her lack of ability. When individuals are severely physically handicapped or carry obvious physical signs of retardation, allowances are made spontaneously for their condition. This finding was similar for the families and siblings in the private college group. The adjustment of both the family and the siblings was greater, the more severe the retardation, especially when the child carried the obvious physical signs of retardation. It appears that ambiguity is reduced as to care and expectations when the child is severely as opposed to moderately or mildly retarded.[23]

Overall, the study found that approximately 45% of the siblings of a mentally handicapped child had been harmed by the presence of the retarded child in the home.

> "Some of the psychological costs we noted include shame about the handicapped child, and guilt about the shame; a sense of being somehow tainted or defective; a sense of guilt for being in good health and, more often, for harboring negative feelings about the retarded child; a feeling of having been neglected by their parents, who were preoccupied with the handicapped child; and at times a strong belief that the handicapped child has put considerable stress on the parents' relationship, which in turn negatively affected the rest of the family."[24]

On the other hand, Grossman noted that approximately 45% of the siblings were judged to have benefited by the experience. Those who had benefited were judged to have developed a greater empathy towards people, more tolerance and compassion in general, and more sensitivity to prejudice. Additionally, many had found career goals in special education or related fields.[25]

Summary and Conclusions

The birth of a mentally retarded child is a traumatic experience for the parents. The initial feelings of shock, grief, guilt, and shame, give way to a general sense of depression, lowered self-esteem and a lack of enjoyment of the handicapped child. Sensitive informed counseling is necessary, not only immediately but throughout the life cycle of the family.

The thrust of early intervention programs with high risk infants is towards helping the parents stimulate their child to maximize cognitive and social/emotional development. It would not be too difficult to expand the functions of these programs to provide the necessary counseling for parents and siblings of the handicapped child.

Group counseling both for parents and siblings has been shown to be highly

effective in helping parents and siblings express their feelings, including anger and frustration, with regard to the handicapped child. Bringing parents together with like problems also facilitates parent to parent counseling and assistance.

Piecemeal efforts designed to aid the mentally handicapped child and his/her family are no longer tolerable. Professional services need to be provided to the whole family in a coordinated manner. Communities need to assume the responsibility of coordinated services for the family of a mentally handicapped child. Only in this way can we alleviate the stress parents feel and the uncertainty and confusion in the minds of the normal siblings.

Footnotes

[1]Alan O. Ross, The Exceptional Child in the Family (New York: Grune and Stratton, 1964), p. 101.

[2]Ibid., pp. 51-70; Harold D. Love, Parental Attitudes toward Exceptional Children (Springfield, Illinois: Charles C. Thomas, 1970), pp. 27-40; Bernard G. Suran and Joseph V. Rizzo, Special Children (Glenview, Illinois: Scott, Foresman and Company, 1979), pp. 398-416; R.N. Emde and Craig Brown, "Adaptation to the Birth of a Down's Syndrome Infant," Journal of the American Academy of Child Psychiatry, 17, (Spring 1978), pp. 299-323.

[3]Love, op. cit., p. 35.

[4]William Brassell, "Intervention with Handicapped Infants: Correlates of Progress," Mental Retardation, 15 (August, 1977), pp. 18-22.

[5]Simon Olshansky, "Chronic Sorrow: A Response to having a Mentally Handicapped Child," Social Casework, XLIII, No. 4, (April, 1962),pp. 190-193.

[6]Kathryn A. Gorham et. al., "Effect on Parents," Issues in the Classification of Children, Nicholas Hobbs, editor (San Francisco: Jossey Bass Publishers, 1975), p. 164.

[7]Fern Yosser Kupfer, "A Place for Zachariah," Redbook, (January, 1980), p. 138.

[8]Ross, op. cit., p. 114; Francis Kaplan Grossman, Brothers and Sisters of Retarded Children (Syracuse: Syracuse University Press, 1972), p. 173; Carolyn M. Fowle, "The Effect of the Severely Mentally Retarded Child on his Family", American Journal of Mental Deficiency, Volume 73, No. 3, (November, 1968), pp. 468-473.

[9]Grossman, op. cit., pp. 156-174.

[10]Kupfer, op. cit., p. 137.

[11]Love, op. cit., p. 31.

[12]S. Thomas Cummings, Helen C. Bayley, and Herbert E. Rie, "Effects of the Child's Deficiency on the Mother: A study of Mothers of Mentally Retarded, Chronically Ill and Neurotic Children," American Journal of Orthopsychiatry, 36, No. 4, (October 1966),pp. 595-608.

[13]S. Thomas Cummings, "The Impact of the Child's Deficiency on the Father: A Study of Fathers of Mentally Retarded and of Chronically Ill Children," American Journal of Orthopsychiatry, 46, No. 2, (April, 1976), pp. 246-255.

[14]Ross, op. cit., p. 69.

[15]Regi Haebig, "The Special Stress that can Break or Make a Marriage," Parents Magazine, Vol. 53, (February 1978), p 26.

[16]Grossman, op. cit., p. 23.

[17]Ibid., p. 37.

[18]Ibid., pp. 23-24.

[19]Ibid., p. 174.

[20]Ibid., pp. 34-35.

[21]Ibid., pp. 35-36.

[22]Ibid., p. 47.

[23]Ibid., pp. 91-117.

[24]Ibid., p. 96.

[25]Ibid., pp. 92-93.

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